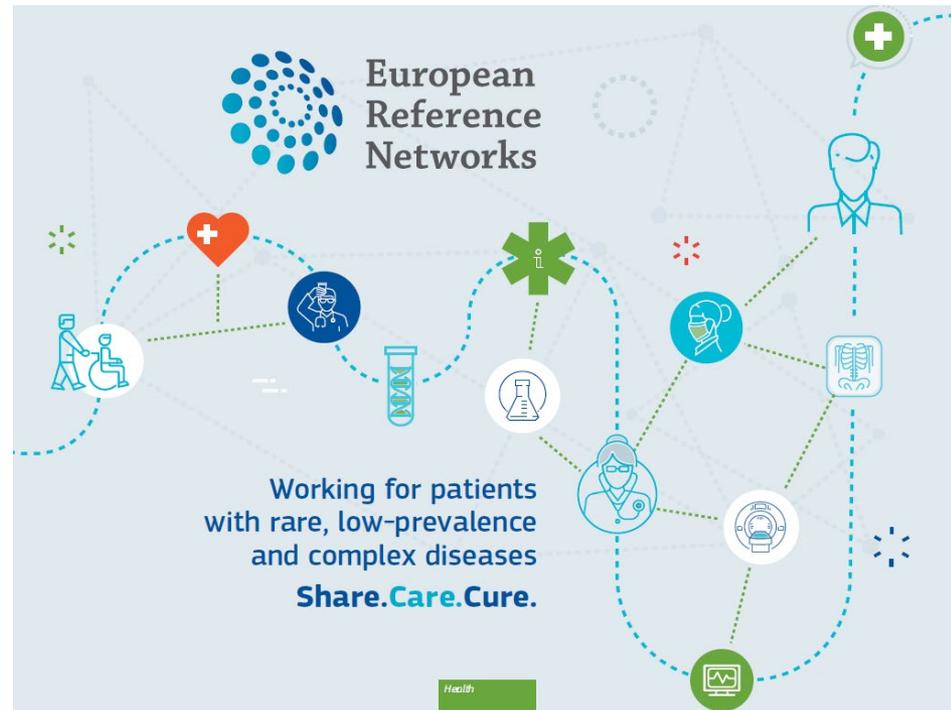


ERNs' main challenges for the future

An ERN coordinators perspective

Alberto M. Pereira
Endo-ERN coordinator
4TH ERN CONFERENCE
BRUSSELS, 22-11-2018



I have no actual or potential conflict of interest in relation to this
program/presentation



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Network**

for rare or low prevalence
complex diseases

European Reference Networks

linking centres of expertise, professionals, and patient organisations in different countries to share knowledge and identify where patients should go

when expertise is unavailable in their home country

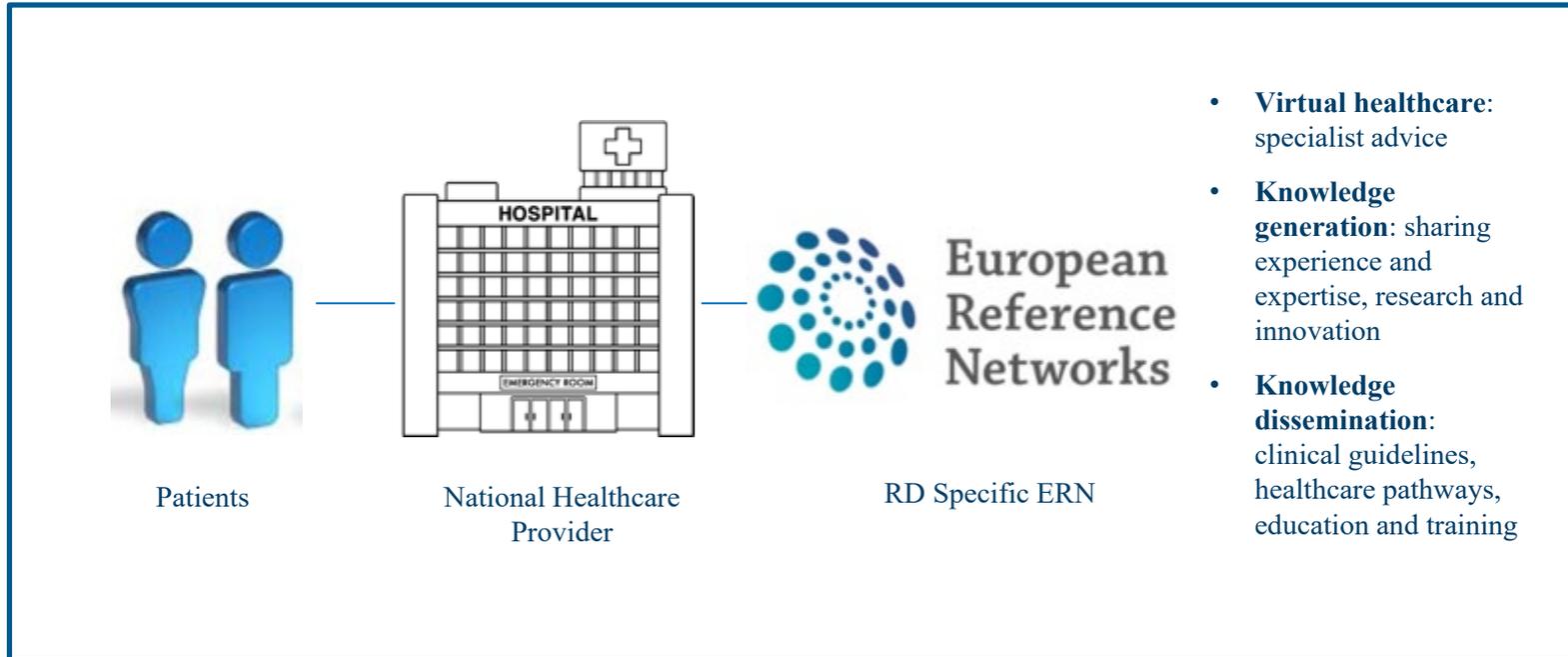
Ultimate aim:

to reduce health inequalities across the EU



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Note: Slide inspired from Dr Enrique Terol, DG SANTE, EU Commission



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Directive 2011/24/EU of patients' rights in cross-border healthcare

- All EU countries have national contact points
- 5 draft scenarios envisioned



Did you know?

You have the right to receive medical treatment in another EU Member State and the right to have your home country cover some or all of the costs.

You have the right to be informed about the treatment options open to you, how other EU countries ensure quality and safety in healthcare, and whether a particular provider is legally entitled to offer services.

Look inside to find out more...

Health & Consum



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- How are ERNs 'sold':
 - free of charge
 - knowledge travels

These are discrepant ideologies!



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- Non-sustainable for the future of ERNs
- Obstructs the effectivity and impact of ERNs for patients with rare conditions

 Continued health disparities



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CPMS as provided by the EC is an excellent tool for virtual care by healthcare providers

Main challenges:

1. Ensure that all HCPs participating in ERNs across all MS have clear consent, and do not encounter any legal barriers to use the CPMS system
2. HCPs need an adequate reimbursement system agreed upon by all MS to ensure use and promotion of virtual consultation through CPMS



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Therefore:

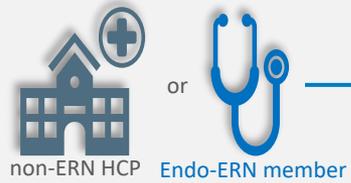
We propose that national healthcare systems in all MS should adopt and enforce a **“CPMS first” policy** to rare disease cases, for which cross-border healthcare is considered



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ERN supported patient care path



Yet some cases are too rare and/or complex and warrant a broader team with specific expertise

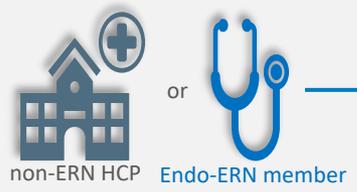
Most cases are effectively handled by local doctors, organized under National healthcare structures



ERN

Can local doctors provide the best care?

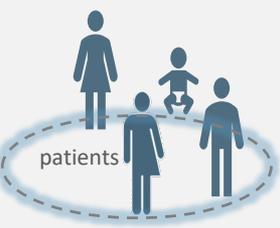
ER N supported patient care path



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Can local doctors provide the best care?

What is specifically needed for this individual patient?

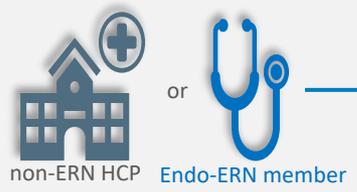
Entry of a case into the ERN Multi-Disciplinary Expert Team (MDT)

ER N

ER N Operational Helpdesk

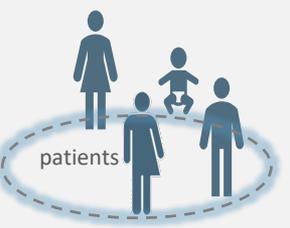
Clinical Patient Management System

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Virtual consultation

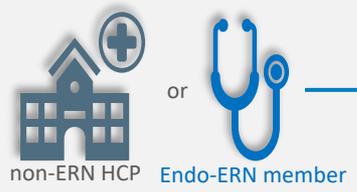


MDT



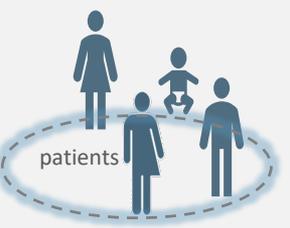
Expert / Specialist Laboratory Analysis and Guidelines

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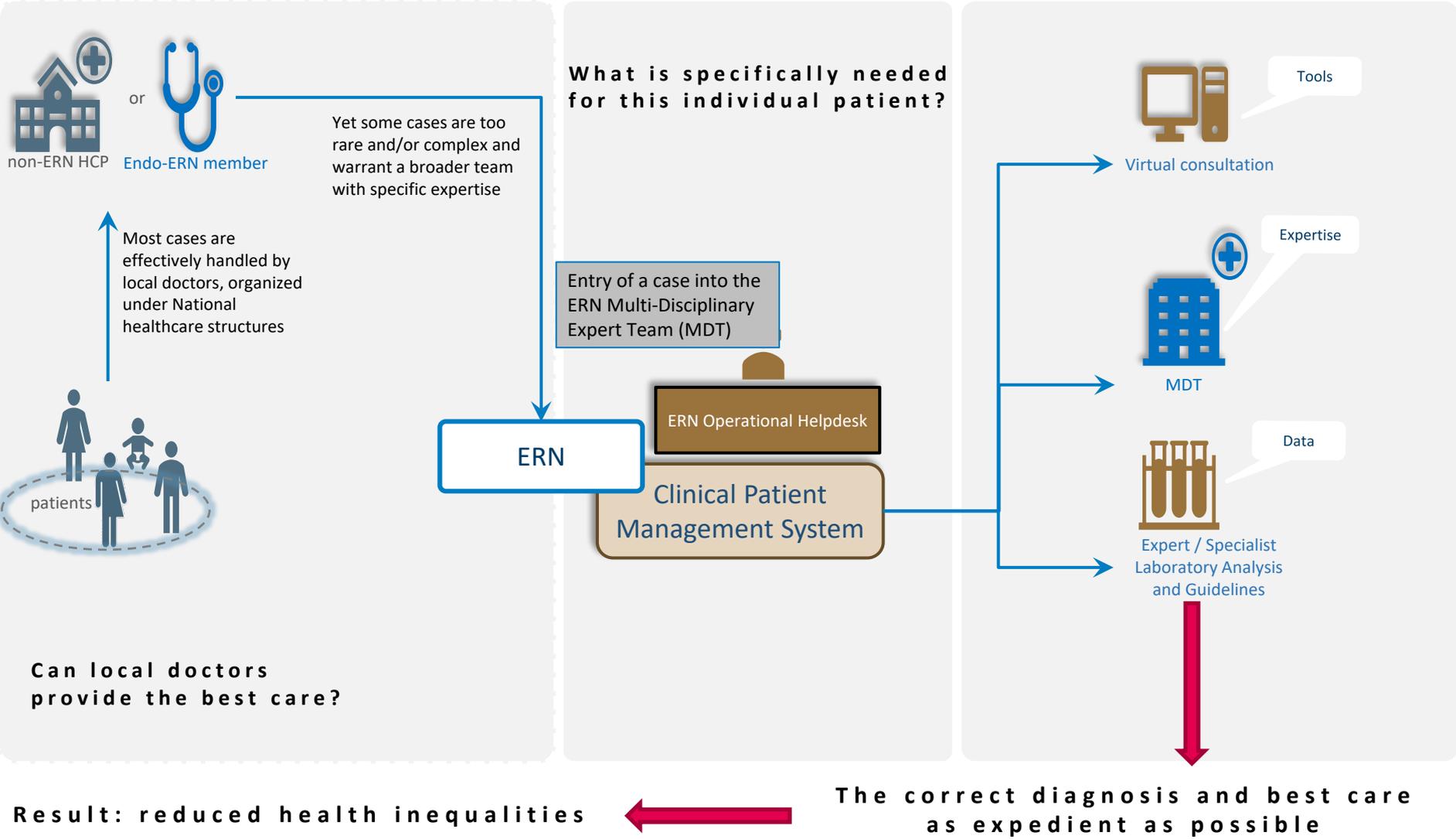


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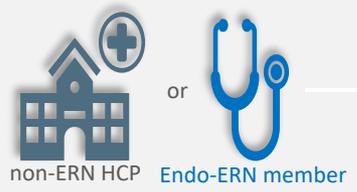


The correct diagnosis and best care as expedient as possible

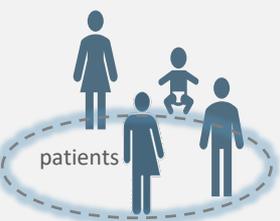
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Virtual Patient Management System



How to reimburse?

Can local doctors provide the best care?

Result: reduced health inequalities

The correct diagnosis and best care as expedient as possible

- System with pre-defined price agreements (like in the Netherlands).
For each specific type of patient care there is a maximum reimbursement.



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- System in which the difference in costs is being payed
from the principle of solidarity out of a EC-based healthcare fund:
ensuring equal access to ERN expertise across different GDP MS.



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Spin-off at the national level:

- education
- participation
- and increased awareness and expertise at all levels!



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Ensure the greatest possible alignment of Member States accreditation criteria for centres of expertise with the operational criteria for ERN full members

discrepancies within countries with different quality standards and mismatch between the national expertise centres and the ERN endorsed full members



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Adjust/Develop RD National Plans to allow an effective integration of ERNs into national health systems

- Identify required changes in national policy and legal frameworks
- Define patient pathways in national networks aligned to the ERNs
- Establish **rules for the referral**
- Establish **national coordinators** (experts-in-the-field) as linking pin between the ERNs and national networks/RD plans



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THANK YOU!

